

## Support in the community

### Guidelines for Support Group Leaders

We recognise that the safe place and peer support you provide to others throughout their sarcoma journey makes a big difference. Sharing experiences, both good and bad, can really help patients and their families to feel less alone, and to feel listened to and understood.

This guide was written in collaboration with experienced group leaders. The team at Sarcoma UK would like to thank all support group leaders for your commitment to supporting others within the wider sarcoma community.

This booklet aims to provide best practice advice in setting up a support group. It offers guidance on how to set up and run a support group and outlines the role of a support group. It also includes tips on how to make sure you take care of yourself while supporting others. You may like to share this guide with others who are thinking about setting up their own support group.

## How to set up a support group

### Who can run a support group?

Anyone can run a support group, and this includes:

- Patients
- Carers
- Family and friends
- Health professionals

Running a support group can be a big commitment. As it is a voluntary role, it's important to recognise the time and effort required to keep it going before you set one up. If you know of several people in your area who are interested in starting a group, it's worth thinking about whether there are several people who could commit to running it together and sharing the responsibility.

### Where can I hold a support group?

A support group can be held anywhere. For example:

- A hospital
- A cancer charity's support and information centre
- A community centre
- A coffee shop

It's important that groups meet somewhere that offers privacy and a safe space.

Choosing a meeting place where members can talk and listen while enjoying a cup of tea or coffee can help new members feel more welcome.

If there are good public transport links and a car park nearby, it is one less thing for members to worry about.

### Is there a good time or day of the week to hold my support group?

There is no right or wrong time to hold your support group. It's useful to think about what time of day most of your members can come to meetings.

More people may be able to come at weekends or in the evening after work. Others may prefer meetings during the day if they don't live locally.

It's important to be consistent with the timings of meetings. For example:

- The first Monday of every month, 6.30-8.30pm
- The third Saturday of every other month, 1.30-3pm

This helps regular members to be sure of when the next meeting will be, as well as those who haven't come to your group for a while and people looking to attend for the first time. Consistency can also help when you are booking a meeting place, as it helps venue organisers to know in advance.

Meetings can last between 90 minutes and 2 hours, and some may meet once a month or every few months. Making sure that meetings run to time helps people to plan the meeting around their other commitments. You may like to send reminders out about the meetings to regular members and your Clinical Nurse Specialist, who can promote your group to new patients.

Some groups also arrange social activities outside of the group meetings. This can help members get to know each other better and provide extra support between sessions. It also gives people a chance to enjoy a day out, away from a hospital or more formal setting, and can help them feel less isolated.

### **Do people who attend a support group have to live in the local area?**

To access the right care and treatment, sarcoma patients need to visit a sarcoma specialist centre. Their nearest centre may be a long way away from where they live because there aren't that many in the UK and they are spread across the country.

It's common for support groups to be held in or near to these specialist centres. You may find that people have travelled to your area to attend an appointment, and they will start coming to your group regularly if there isn't one closer to their home.

Some people don't live locally and can't travel to attend your meetings, even though yours is the closest support group. You can let them know about online support groups such as [Sarcoma Patients in the UK and Ireland](#) (Facebook group), [Macmillan Cancer Support Community](#) and [Desmoid United](#) (Facebook group). More information about these online support groups can be found on the [Sarcoma UK website](#). You can also suggest that they ask their Clinical Nurse Specialist about other local sources of support.

### **How do I fund a support group?**

Sarcoma UK offers a grant of £500 a year. This can be used to pay for:

- Travel expenses
- Room bookings
- Get togethers
- Trips out
- Promotional materials

To find out more about this grant, or to apply for funding, please contact Laura, the Information and Support Officer at Sarcoma UK at [laura.hart@sarcoma.org.uk](mailto:laura.hart@sarcoma.org.uk)

There are organisations such as local authorities, trusts and charities who may offer funding. There are also informal ways of fundraising, such as pub quizzes and raffles, with family and friends, colleagues and local hospital teams. The Sarcoma UK fundraising team can offer further information and advice on accessing other sources of funding. Please contact them at [fundraising@sarcoma.org.uk](mailto:fundraising@sarcoma.org.uk)

### **How should I store confidential information about group members?**

It's very important that you store confidential information about group members in a way that follows the Data Protection Act 2018 and the General Data Protection Regulation. This is commonly known as GDPR.

Detailed information about GDPR and how to make sure you're following it can be found at: <https://www.resourcecentre.org.uk/information/data-protection-for-community-groups/>

## **The role of a support group**

### **What happens at a support group?**

There is no 'right' way to run a support group.

Support groups usually:

- Provide a safe place for members to feel heard and share experiences
- Allow members to ask questions where people can really understand
- Give information about sarcoma from trusted sources, such as information produced by Sarcoma UK
- Welcome members for many reasons at different stages of their journey with sarcoma
- Provide a community for sarcoma patients and their loved ones

However, there are also differences:

- Some support groups have a formal agenda for meetings, and some are more informal
- Some host social activities outside the meetings and others don't
- Some groups have guest speakers followed by discussion and chat, and others use their meetings for conversation between members

Members shouldn't feel they have to share their experiences with the group if they don't want to. The important thing is that people feel comfortable and included.

When people do choose to talk about their experiences, it's important that the whole group respects their confidentiality, and as a group leader, it's best to mention this at the start of each session.

### **Do support groups provide medical advice?**

Support groups are a safe place for members to give and receive support but they can't replace medical advice or offer second opinions. For some, a support group can offer a welcome break from hospital appointments.

Some support groups are run by Clinical Nurse Specialists who may be able to give specialist advice. You can point members in the direction of their own Clinical Nurse Specialists if they have any questions you feel you can't answer. Support group leaders can also direct members to Sarcoma UK's [Support Line](#) for advice and support.

## Running a support group

### How do I advertise my support group?

There are different ways to advertise your support group. These can include:

- A website
- Social media
- Printed materials such as leaflets and posters, to place in a local hospital
- You can ask your sarcoma Clinical Nurse Specialist to direct patients to your group.

If you would like to advertise your support group online using social media, it's important to know about safeguarding. You can find out more about this at: <https://www.bond.org.uk/resources/safeguarding-guidance-resources-and-tools>.

The Communications Team at Sarcoma UK have also produced some resources for group leaders, which you can [download](#) from the Sarcoma UK website.

### What support does Sarcoma UK provide to support group leaders?

We understand that running a support group can be challenging and leaders may need extra support. Group leaders or anyone interested in setting up a group can contact our Information and Support Officer at [laura.hart@sarcoma.org.uk](mailto:laura.hart@sarcoma.org.uk)

Sarcoma UK's confidential [Support Line](#) is here for anyone affected by sarcoma, including support group leaders, who we can point in the right direction.

- Our support line is independent and confidential
- We believe no question is a silly question
- We lend a listening ear

We host Support Group Leader days where leaders can learn skills, meet others, and share their experiences.

**The following sections were written by Jo Ham, Emotional Wellbeing Consultant and Psychotherapist.**

### How do I deal with difficult situations and emotions?

In the course of running a sarcoma support group, you're likely to come across a full range of different emotions. Each member at the meeting will be at varying stages in their sarcoma journey. They will bring their own concerns and challenges, which could range from the recently-diagnosed to the bereaved, and everything in between.

When someone is clearly upset or struggling, the best thing you can do is offer a sympathetic listening ear. Acknowledge that what they're going through is very difficult and that you can see that they're upset. Feeling heard can be very soothing in itself and the person isn't expecting you to solve the problem or provide a magic wand. The very act of being listened to will help the person to calm down and feel a little better.

Here are some guidelines:

- When a person is clearly very upset, just listen calmly and sympathetically. Try and summarise what you think they're telling you, focusing on the emotion behind the words they are using. This will help them to feel heard and understood. Once they are feeling a little calmer, you may be able to begin to explore with them what steps they can take in their current situation.
- Relax and trust yourself to provide a listening ear to the members of the group. This in itself is a wonderful and valuable form of support.
- Make sure you practice self-care techniques such as those outlined below, so you can keep yourself emotionally healthy.

## Looking after yourself

### How do I protect myself and keep myself safe?

It's important that everyone in the group listens to other members and shows appropriate empathy. However, as group leader, it's also vital to make sure you keep yourself emotionally calm and don't get too drawn into other people's problems. It's about finding the balance between showing empathy and support and making sure you don't take on everyone else's troubles.

There are lots of ways to protect yourself, involving simple techniques for keeping emotionally healthy. Here are some suggestions for lifting your spirits and staying emotionally resilient:

- Get outside every day, and keep as active as you can. Depending on your mobility, going outside gives us fresh air, natural light and a little bit of exercise. It gives us a change of scene and a sense of perspective.
- Connect with other people. Talk to a friend or family member, go for a coffee, join a club. Connecting with others is a great mood booster.
- Try and do one act of kindness each day. Focusing our attention on others is a great way to keep busy and positive and can give a lovely sense of achievement.
- Take up a new skill or hobby. It doesn't matter what it is, just think about something you've always wanted to learn, and try it. This is a great way to keep emotionally healthy.
- Practice mindfulness. There are lots of online resources and short meditations to help you stay calm and keep worrying under control.
- Notice difficult feelings and acknowledge them. Name the feeling. Give it a number out of 10. Practice calming breathing and imagine you are in your favourite relaxing place. Then revisit the feeling and notice how the number will probably have gone down.
- If a feeling is proving too difficult to manage with the above self-help techniques, it's sensible to get some professional help or phone the Sarcoma UK Support Line for advice.

- And finally, make sure you do something other than running a sarcoma support group! Whilst it's a wholly worthwhile thing to do, it's important for you to keep perspective in your life and have other things that take you away from the group and bring you enjoyment and relaxation.

The Information and Support team at Sarcoma UK would like to thank all support group leaders who contributed to this guide. For further information about support groups, please contact Laura, the Information and Support Officer, at [laura.hart@sarcoma.org.uk](mailto:laura.hart@sarcoma.org.uk) or the Support Line team on 0808 801 0401 or at [supportline@sarcoma.org.uk](mailto:supportline@sarcoma.org.uk)